With

HOPE

and

HELP

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Manual for Communities

For facilitators and community groups
To accompany the video "With Hope and Help"
This manual is aimed at promoting true understanding of
People With HIV/AIDS

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"With Hope and Help"

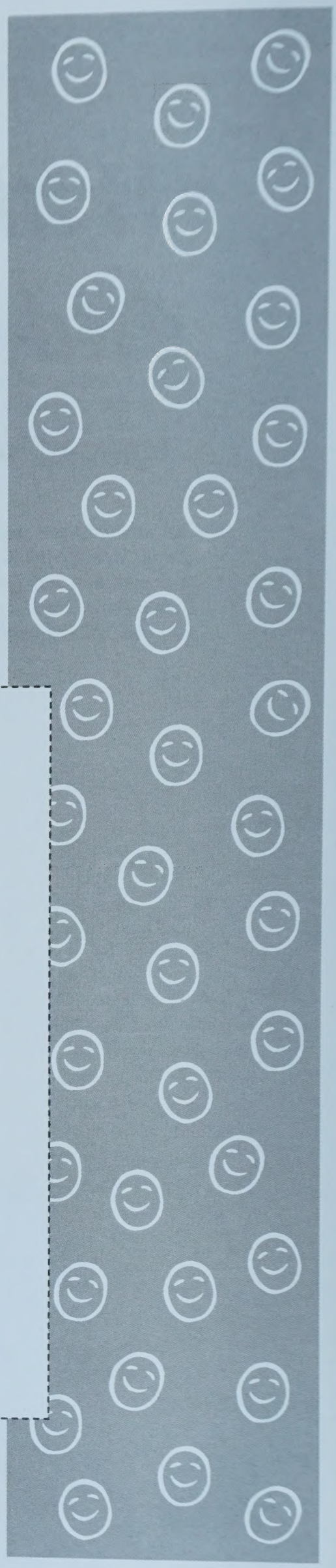
Manual For Communities

This manual was compiled by the Education and Counselling specialist staff from the Albion Street Centre, Sydney in conjunction with the Counselling Staff of Bamrasnaradura Hospital, Nonthaburi with assistance from the UNICEF Regional Office for East Asia and the Pacific.

To accompany the video "With Hope and Help"

This manual is aimed at promoting true understanding of people with HIV/AIDS in and among communities. The manual is designed for all those close to people living with HIV/AIDS, whether friends, neighbours, relations, employers or health care providers. The manual provides communities with an insight into the social, physical and emotional problems faced by HIV positive community members, as well as practical advice to address such problems. In addition to information and advice, the manual includes group activities which explore ways to create a supportive environment for people living with HIV/AIDS.

"With Hope and Help"



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Foreword

None of us deserves to be excluded from society because we have an illness or even just the germ of an illness in our bodies. This is the kind of exclusion people with HIV and AIDS are now experiencing. Those who imagine that they themselves are far removed from such a plight are the very ones busy excluding and discriminating against people with HIV and AIDS. Such people lack true understanding.

True understanding is the best cure society can provide to solve the very worst of problems. Everyone fears pain and suffering. We all fear death even more. But, most of all, people fear the living death that is caused when a person is excluded from the society in which they have lived their life.

This manual which accompanies the "With Hope and Help" video has been designed to give group leaders ideas and direction to run activities and discussions. The manual addresses misconceptions about people who have HIV and those sick with AIDS. The manual will be used with groups of leaders in society and with communities so that they can gain a true understanding of what it really means to have HIV. This is the sort of understanding that will open the gates of loving kindness and will be followed by the best help and support possible.

If you have HIV, the manual will help build your self-awareness and increase your understanding of your situation, which will lead to better care of your physical and mental health. It will encourage you to help out friends who are in the same situation. Being independent and caring for yourself is tremendously empowering. If you are able to help your friends and society as well, this can give you life-giving hope and strength.

What the world needs now is understanding. We all need to understand ourselves, our fellow human beings, and our society. From this, loving kindness will proceed. If we can do this, the world will certainly become a happier, more peaceful place.

Dr Chaowalit Natpratan
Director,
Communicable Disease Control Office, Region 10

Acknowledgments

A great many people and many organisations contributed to the process of developing these materials. We would like to thank the people living with HIV/AIDS, the school children and students, the young people in workplaces and communities, members of various communities who sacrificed their time to discuss the video with our production team. We would also like to thank the participating organisations, both those who were represented on the project committee and contributed to the brainstorm process and those who organised meetings with various target audiences:

AIDS Project of the European Union
Asian Development Bank
Association for the Advancement of Children
Banglamung Hospital
Duang Prateep Foundation
Candlelight Club
CARE International, Thailand
Clear Skies Project
Family Health International
Foundation for Increasing Capability of Populace
Gillette, Thailand, Limited
Hyatt Erawan Hotel
Jardine Mathieson, Thailand Limited
Living Films
Minprasart School
Nawamintrachuthit Secondary School
NGO Coalition On AIDS
Nestle, Thailand Limited
Panat Nikom Hospital
Pearl S. Buck Charitable Foundation
Regent Hotel
San Pa Tong Hospital
Thai Business Coalition on AIDS
Thai Red Cross AIDS Program
Thai Spectacles Factory
Wednesday Friends Club
White Dove Association
YMCA

"With Hope and Help"

About this video...

"With Hope and Help" is a 35 minutes video about HIV and AIDS. This inspiring video features intimate interviews with long term survivors confronting the epidemic throughout Thailand.

The aim of this video is to promote community support and acceptance of people with HIV/AIDS. The HIV positive people in the video can show communities that people with HIV/AIDS are ordinary people struggling to maintain their health and well-being, despite having a serious health problem.

What audiences wanted to know about the video

- **Is it true?**

This video is a documentary. The people in this video are not actors. They are not reading from scripts, either. They are real people, who have been brave enough to stand up and talk to us about living with HIV/AIDS. The film maker interviewed a total of forty people with HIV/AIDS for this video, but not all of their stories were used. (You can see the faces of all forty people during the credits at the end).

- **Does everyone on the video have HIV/AIDS?**

There are a few people talking on the video who don't have the virus. These include a monk, a nurse, a doctor, a herbalist, a nutritionist and a traditional medicine doctor, who are all involved in helping people with HIV/AIDS and working with communities to understand their needs.

- **How come they are all from the North?**

The HIV positive men and women in this video are from all parts of Thailand: from cities, towns and villages in the countryside. You may see places you recognise in the backgrounds. There are also a number of people in the video from the North of Thailand. This is because the North was the first region in Thailand to be seriously affected by HIV/AIDS. Now, there are more and more people in the North East and Central and Southern Regions who are also affected by HIV/AIDS. The people in this video hope that people everywhere will be able to learn from their experience.

This documentary was made possible through generous grants from : Care International Thailand; The Australian Government through AusAID; The European Union (ECAIDS) through Mahidol University's Asian Institute for Health Development and UN Thailand Theme Group on AIDS (UNICEF, UNDP, UNFPA, UNESCO, WHO, World Bank).

How come they don't look sick?
The people with HIV/AIDS in the video are healthy and happy now. But as you will see and hear, they have all been through difficult times. Some of them have been seriously ill. Because HIV weakens people's immune systems, people with the virus can get a great many infections (called opportunistic infections). Many of these opportunistic infections can be treated. That is why the people in the video who were sick, look so healthy now, because they have received treatment of various kinds. Positive people need to take good care of their health and in this video, you will find some ideas for doing just that.

- **How come they don't seem to have problems like other people with HIV/AIDS you hear about?**

At first, the people with HIV/AIDS in the video all had a lot of problems. Sometimes families and communities rejected people with HIV/AIDS and treated them badly. They were scared to go near a person with HIV/AIDS. But, as time went on, more people understood that AIDS doesn't jump from person to person like a flea and that they could still eat with people with the virus and care for them if they were sick. Now, the people with HIV/AIDS in the video are able to lead full and happy lives as productive members of society, thanks to the support received from friends, relatives and community members, as well as their own determination.

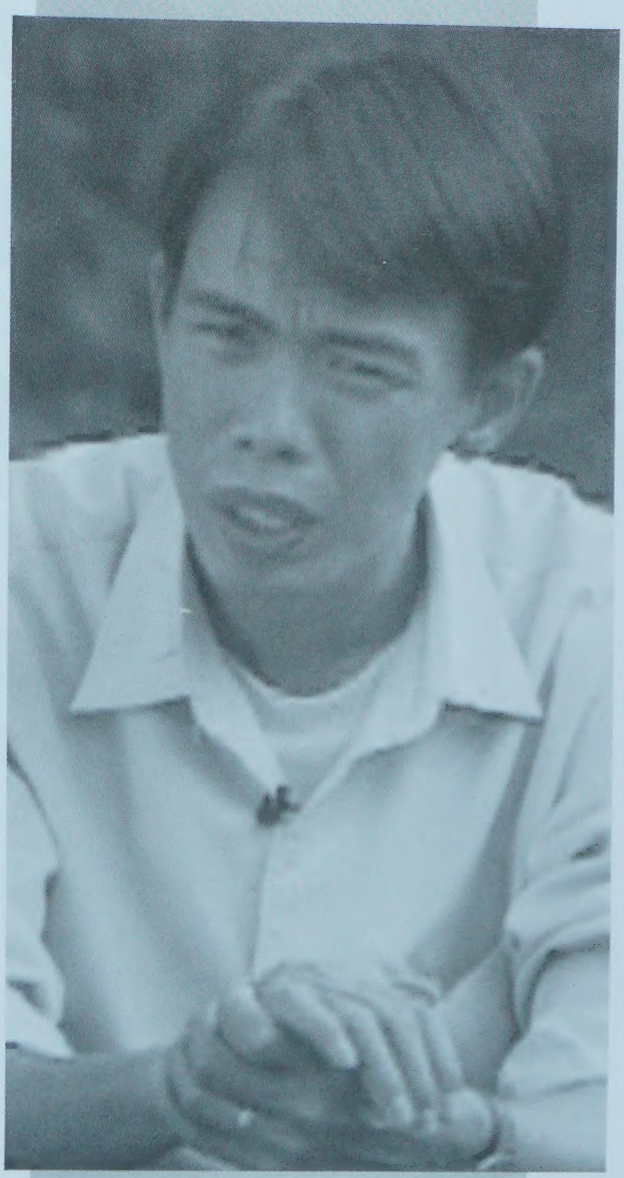
- **What can we do to help?**

We can support our friends, neighbours, workmates and family members with HIV/AIDS. We can give them encouragement and we can try to make sure everyone knows what HIV is really like. There are still some people who don't understand about the virus and who have trouble accepting people with HIV/AIDS. This can lead to people with the virus being treated unfairly, or with hostility, in their homes, in their work or in their communities. We can try to inform communities so that they change their attitude.

In the manual that follows: "With Hope and Help: For Communities", you will find additional information and learning activities to enhance the message of the video for use with community groups, youth groups, school children and health workers. The materials in the "With Hope and Help" series are:

- With Hope and Help, Manual For Communities
- With Hope and Help, Manual For People with HIV/AIDS
- With Hope and Help, Manual on Self-Care, For people with HIV/AIDS and their carers.

All materials in this series are available in Thai and English. Please contact UNICEF EAPRO for distribution details on 2805931, extension HIV/AIDS Unit.



" AIDS is not something that should divide and isolate us, one from another, but something that should bring us together."

Prasert Dechaboon

How to get the most out of this manual

About this manual

This manual was designed to promote the effective dissemination of the message of the documentary film "With Hope and Help" to a wide ranging population. The content, activities and advice that have been collected in this volume are intended to give people with HIV/AIDS alternatives and to inspire them to live with hope. Both the manual and video have been designed to enable people in society, whether they be young people or the general population, or people providing services to people living with HIV/AIDS, to better understand the feelings and needs of people with HIV/AIDS.

One part of the process we used in designing this manual was to run discussion groups to find out what points interested our audiences, what questions they had, and what understanding or opinions they had about people living with HIV/AIDS. We used this feedback to select additional information and develop activities. We hope this manual will assist people to have a positive and realistic approach to problem solving, as well as learning to live in society with people with HIV/AIDS and the HIV virus on a day to day level. The manual was focus tested in a draft form with the range of target groups. We even developed some advice on how to best use this manual to promote discussion and to engage participants in active learning through activities.

Who can use this manual?

This manual is especially aimed at group leaders or facilitators to use with community groups. The group leader or facilitator may be a peer educator, a teacher, a health worker, a volunteer or an interested community member.

Viewers will get the most out of this video if it is followed by discussion and activities which explore viewers' reactions to the messages in the video. It is easier to conduct discussion and activities if the video is presented by a group leader or facilitator.

IN THIS MANUAL...

Topics with background information and activities:

- **Accepting people with HIV/AIDS** ***Activity sheet***
- **Finding Out that you are HIV+** ***Activity sheet***
- **Keeping Well** ***Activity sheet***
- **Being Sick**
- **Mental Health**
- **Nutrition**
- **Herbal Medicine** ***Activity sheet***
- **Employment** ***Activity sheet***
- **Love, Sex and Intimacy** ***Activity sheet***
- **Families**
- **Disclosure** ***Activity sheet***
- **Transmission** ***Activity sheet***

If you have limited time to spend with the group, we recommend conducting the activity "Accepting People With HIV/AIDS" which best reflects the video's message and revising the section and activity on "Transmission".

How to get the most out of this video

Before viewers arrive to see the video...

Time and Place
If you're showing the video during the day, try and pick a spot that is as dark and shady as possible. Indoors is best, but if that is not possible, spend a little time finding the least reflective position for the screen. Videos often look their best at night, when the picture and colour stand out more.

Caution
Don't operate during thunderstorms as equipment may be damaged.

Distractions
If your viewers are busy senior executives in their offices or children during their playtime you may find that the executives want to keep on working and the children want to keep on playing!

Unless viewers are very, very interested in the topic they will be distracted if the video is shown somewhere where there are frequent interruptions or people coming and going. Try to find somewhere quiet where people can concentrate on the video.

Planning
Plan what you will do when the video is over.
In the following pages we give suggestions as to activities you might like to do with the group. However, the group may have its own ideas on what topic they are interested in pursuing. Get them to arrange the list of topics in order of priority. Background information sheets are provided for each topic. Where appropriate we have designed activities to encourage group participation. Use the activity sheets to get the group started with discussions.

TOOLS:

Videos need electricity or a generator, to operate. Check that the place you want to show the video has power and a VCR and TV in working order.

Before viewers arrive, make sure equipment is working, that the video is tuned, connected correctly to the TV etc.

When you start the video, check that people at the back can see and hear.

Before you show the video…

Preparing yourself

Make sure you know who will be viewing the video, how old viewers will be, what level of education they have, how much experience they have of HIV/AIDS.

Community Groups:
It is increasingly likely that general community groups will include either positive people who chose not to disclose their status or relatives of people who have HIV or are sick or have died. Group leaders may try and remember to include these perspectives in their presentation. Some terms that were used in Government campaigns early in the epidemic can offend people with HIV/AIDS or make them upset. Avoid phrases like "Only promiscuous people get AIDS". Emphasising the difference between "innocent victims" like wives and children and "guilty" people who may have acquired HIV through drug use or sex outside marriage, can make people feel rejected and excluded.

You need to:

- have seen the video;
- have a good idea what issues your group will be interested in and what issues you want to highlight;
- know how long each activity takes. There are many activities in this manual and you will not be able to do them all in one session;
- have ideas on how you will conduct the session: how you will move from viewing to discussion; whether you will break up into small groups after the video etc.;
- have any handouts ready to give out after the session (if you give these out before the session people will spend first five minutes of the video reading handout);
- know who the relevant contacts are in your area. You can use these contacts to refer people to, if they need further support or information;
- you can prepare participants by telling them the questions you will be asking them after they have viewed the video. For instance…

  "After you've watched the video I want you to tell me who your favourite person was."

Preparing your audience

On a practical level:
Viewers need to know the video takes 35 minutes and how long you want them to stay afterwards, as well as what the video is about and where it comes from. Go through page4-5 "About this video", beforehand.

People are more likely to be interested in the video if they feel it is relevant to them. To make it relevant, introduce the video with a story about a local incident, or ask participants if they know any stories about people with HIV/AIDS or give the local statistics on HIV.

On an emotional level:
Group members are likely to experience a range of different feelings and thoughts as they watch the video and in the discussions that follow. It's helpful if you, the facilitator, can prepare the group for this.

- Inform the group that previous experience has shown that some people may become distressed as they watch the video and compare their own situations to those people sharing their stories in the video.
- Inform the group that they can debrief about the different feelings and thoughts they experience following the viewing of the video.

During the video...

Problems can occur!

- Viewers can ignore the video completely.

In this case it may be better to switch it off and talk about the topic instead.

- Some viewers may watch and others not.

In this case you may ask the group whether they want to keep watching or come to an arrangement that allows those who want to continue and take part in discussion to do so, while others can leave or find something else to do.

- Pay attention to the body language of participants. You may notice participants who are moved or upset by the material, or they may quietly leave.

HIV/AIDS raises lots of sensitive issues. Sometimes, as the facilitator, it's hard to know what to do when people react strongly to the video. That's why we have included some suggestions for ways you can help follow-up participant's needs in the sections entitled "De-briefing" below.

- Some people may feel they need to discuss taking a test for HIV antibodies.

You should have contacts they need and be prepared to refer them to an appropriate testing place , where pre and post test counselling is available.

After the video…

Before you carry on with discussion or other activities you may give the group time to explore the feelings and thoughts raised by the video. Many group members may have not had previous opportunities to explore these feelings and thoughts. Some people may feel sad or angry. It is important not to joke about people's reactions or try to force them to feel better. Instead allow them to experience these feelings and thoughts in a supportive environment that can assist them to cope with their reactions in a productive manner.

Exploring Feelings

Ask the group to spend some quiet time considering their feelings.

- **Let group members express their feelings:**

You may choose to go around the group and ask each member to give one or two words that best describes their reaction to the video.

- **Acknowledge the feelings expressed:**

"So it seems there is a range of feelings in the group after watching the video…"

"It seems that while there are a **range** of feelings in the group, **many** people are feeling …."

"I can see some group members are ……. (upset, sad)"

- **Normalise these reactions:**

Let the viewers know that you understand why someone might feel that way. For instance:

"These feelings are understandable given the stories we have heard and the many issues related to HIV."

"These feelings are a normal reaction to HIV issues."

- **Viewers who don't want to talk about feelings:**

Viewers may also not demonstrate any signs of being upset or affected by the video, especially in a larger group. You may describe some responses that other people have had and acknowledge that in a large group it's hard to talk about feelings. For instance:

"Some people watching the video felt sad when they saw K. Pimjai and her family, because they felt that their family wasn't like that…"

You may then move on to the activities.

WHAT TO DO WHEN…

- **Only one or two people are upset:**

Ask the person if they would like to discuss their feelings within the group or whether they would prefer to talk with you individually after the group or in a break;

OR

Approach the person after the group or in the break, express your concern about them and ask if they would like to spend some time talking with you.

- **No-one is particularly upset:**

Move on to discussion, or start one of the activities we suggest, on the topic that the group is most interested in…

- **More than two people are still upset:**

Continue with the de-briefing techniques on the next page.

You can also come back to the de-briefing section at any time. It's often a good idea to run through it right at the end of the session to make sure everyone is ok to go home.

After the video... de-briefing

Strategies for Feeling Better

Ask the group to consider what strategies or 'plan of action' can help them deal with some of the uncomfortable feelings they may have experienced.

- You may choose to again go around the group asking each member to share a 'strategy' or course of action or activity they find useful for them when they are upset, angry, worried, etc.
- As the facilitator, you may need to add some strategies to those generated by the group if they are having difficulty, like: talking to someone, phoning a friend, reading, exercising, eating or drinking something nice, watching television, listening to music, doing something they enjoy.
- You may just open this issue for group discussion.
- You may decide to ask them to break into pairs or small groups to discuss this.

Are participants ready and able to go home?

Debriefing/exploring feelings
Reassess how people are feeling – you may again choose to go around the group and ask each group member to use one or two words to express their current feelings.

If group members continue to show distress you will need to discuss whether they are able to return home safely.

★ Check how group members intend getting home.

★ Alternative arrangements may need to be made to ensure people's safety, eg. people may be too distressed to ride motorbikes or drive.

★ For some people it may be helpful to delay their return home – have a cup of tea, go for a walk.

★ You can also use your contact list to suggest places to go for help.

CONTACTS

It is essential that you have a list of available contacts in your area so you can refer group members for further assistance and professional support as required.

Accepting people with HIV/AIDS

Activity Sheet

Facilitator

1. On a board write the heading:
"Problems for People With HIV/AIDS"

2. Prompted Recall of Problems from Video
Ask participants to think back to the video. Ask if they remember what problems people had:

- "Do you remember the man in the striped shirt? What problems did he have?"

(Viewers generally remember that his weight went down to 34 kilograms – Ask how much they weigh. Get them to realise that the man was the weight of a ten year old child.)

- "Do you remember what health problems Prasert had?"

(Viewers generally remember that he nearly died.)

- "What about social problems that people experience?"
- "Do people with HIV find it easy to get work?"

At this stage your list should include:
sickness, weight loss, discrimination, difficulty in employment, rejection by community.

3. NOW ask the following key questions:

- Ask if they remember the woman in the green shirt from Samut Prakan … "What were her problems?"

(Viewers remember that she tried to kill herself.)

- Ask the group **why** she wanted to kill herself? List:
  - She thought she would die quickly, in 4-5 days.
  - She didn't want to have sores all over her.
  - She was 4 months pregnant.

4. Then write up a new heading:

"Causes of Problems"

Ask the group what they think **caused** the woman's problems and write up all the answers, including:

- Lack of knowledge about the disease
- Fear of visible symptoms that lead to rejection
- Scary media campaigns
- Anxiety over her child's future

Ask : "What are the causes of Prasert's problems and others' problems?"

Now, your list of causes should include:

- fear of people with AIDS, judgemental attitudes towards positive people
- illness
- poverty, lack of resources
- lack of access to medical care

Keep that sheet of paper on display.

Accepting people with HIV/AIDS

Activity Sheet

Facilitator

5. **Now on another big sheet write up the heading:**

"Ways we can help"

Ask the group " What do you think you can do to help people with HIV/AIDS?"

Your list could include the headings:
- Increasing Knowledge
- Changing Attitudes and Beliefs
- Providing Opportunities.

Increasing Knowledge could include:

- Treatment and care options.
- How to help positive people stay healthy and have healthy babies.
- Safe sex information.

Changing Attitudes and Beliefs could include:

- Understanding and accepting people with HIV and AIDS.
- Not judging people on the basis of their assumed or known risk behaviour.
- Getting other people to understand HIV better.

Providing opportunities:

- Access to care.
- Employment opportunities.
- Benefits for people who are sick.
- Positive media messages about people with HIV.

Accepting people with HIV/AIDS

Activity Sheet

Facilitator

(30 minutes)
1.Give out the attached sheets.
How Should Society Treat People with HIV/AIDS
2. Ask each participant to fill in both sets of boxes with his/her individual response to the question asked.
3. Ask them to divide into small groups to share, compare and discuss their individual responses and prepare a group response.
4. Ask them to come back to the big group and ask each group to share its conclusions.
5. Look at the reasons society treats people with HIV/AIDS differently and reasons for the way you would treat them.

How Should Society Treat People with HIV/AIDS
Fill in the boxes to indicate your response to the following two questions. When you have done this, divide into groups and work out your group response.

Use the numbers 5 4 3 2 1
Where 5 = A person with HIV should be treated differently; and
Where 1 = A person with HIV should be treated like everyone else.

A. How do you think you should treat a person with HIV?

Individual response: 5 4 3 2 1	Group response: 5 4 3 2 1
Socially	
Medically	
Legally	
Educationally	
In Employment	

B. How do you think a person with HIV is actually treated by society, today?

Individual response: 5 4 3 2 1	Group response: 5 4 3 2 1
Socially	
Medically	
Legally	
Educationally	
In Employment	

Finding Out

(Also see section on Families, page 42.)

"When the doctor told me I was infected, I just laughed! How could I be infected, I'm young and healthy..."
HIV positive woman

For many people finding out they have the virus is a big shock.

Like any serious health problem, it takes a while for a person to adjust to the news that they have the virus.

Immediately after hearing the news some people don't take in information and advice. They need time for the message to sink in. Others can't believe that they have such a virus.

For a long time people didn't understand about the virus and how it affects the body. In the early days of the HIV/AIDS epidemic, many people were confused and thought that if you contracted the virus, you had to get sick and die instantly.

People can remember all these messages when they are told they have contracted the virus and this can be a very anxious time for them.

In fact, it is not true that people with HIV become sick or die a short time after contracting the virus. In the video you have just seen, there are many people, men and women, old and young, who have had the virus for years and years. The man who has had the virus for longest in the video has had it twelve years. Others have known they have been infected for eight and nine years.

As one woman said

"I've been positive for 8 years now, it's not just one or 2 days you know."

In America there is a long term survivors group for people with HIV who've lived up to 20 years without even getting sick.

QUIZ QUESTION
What's the greatest number of years that someone in the video has lived knowing that they had the virus???

Finding Out

Advice for families and friends
You may be close to someone with HIV who's just told you that they are HIV positive. They may be well, with no symptoms of any kind or they may have been sick and got better or be sick now.

This may have been a shock for you, or you may have already known or thought of this possibility before. You may be the only person in the family who knows. If you've been asked to keep it a secret, remember that trust is very important. If you are upset, it can be hard to keep a secret. You could make an anonymous call to a HOTLINE. Sometimes it's best to be honest with the person who is confiding in you, and tell them that it will be difficult for you to keep this information to yourself.

It takes time to accept that someone close to you is HIV positive and learn to be supportive. Many people who find out that they have HIV feel isolated or scared. Sometimes they want to talk about HIV and how they are feeling, sometimes not. Each person is different. There is no one right way to help. Some ways that families and friends can support people who are newly diagnosed are:

- Offering your support.
- Being responsive to the needs of the person close to you: listening to what they have to say, trying to take your cues from them.
- Remembering that the process of accepting the diagnosis takes time for both of you.
- Giving practical support, like lending money, helping with housework, cooking, cleaning and washing up.
- Diversion: activities that have nothing to do with HIV, like eating out or watching a movie together.

Many people find when adjusting to major changes they experience a range of emotions over time. At different times people can feel angry, disbelieving, sad, resigned, distant, stressed and at some stage, accepting. This is understandable. Be patient and remember that they will probably move through a number of different emotions.

"Well, I'm 60 years old now. They told me I was infected after I got sick four years ago."
Ironsmith

Finding Out

Activity Sheet

Facilitator

How does it feel to have HIV – Role Play

Sunida: You are a young woman who is about to get married. You and your fiance decide to have an HIV test as you plan to have a family one day. The doctor rings you at home to ask you to come in and get the results of the blood test. You find you are HIV positive. You come home in a state of confusion. You walk down to the local community health centre and talk to your friend, Duangrudi, who is a nurse there. You tell your friend that you think you will die of AIDS very soon. You are desperate.

Sunida: Hi, Duangrudi, have you got a few minutes? I need to talk to you!

Duangrudi: Sure Sunida, let's go into the clinic where it's quiet.

Sunida: Duangrudi, I've just got to talk to someone – today I found out that I have AIDS! What about my fiance? We want to have children!

Duangrudi: You are a nurse at the community health centre. You see your old school friend, Sunida, coming into the centre, looking upset. Sunida tells you that she has just been told she is HIV positive. She tells you she will probably die of AIDS very soon and asks you if she can have children now? You have actually never known anybody in your circle of friends who has HIV, although you have nursed AIDS patients before. What do you say?

Sunida: Duangrudi, yesterday I spoke to the doctor, and he says I have AIDS. I am going to die!

Duangrudi: What do you mean you have AIDS. Do you feel sick?

Sunida: No, I feel fine.

Duangrudi: Being HIV positive is not the same as having AIDS. What else did the doctor say?

- Write up the role plays on the board or ask the group to break up into twos and give each person a role-play card to read.
- The two are then to role play being the positive woman and her best friend, the community nurse.
- To help participants we have included some possible opening lines to get things started.
- Participants can act out the scripts below and make up the rest.
- Then bring the group back together to talk about these discussion questions.

Discussion Questions

★ How did Sunida feel about finding out she had HIV?

★ What were the problems she faced?

★ What did she need to know?

How could Duangrudi help her?

Finding Out

Advice for families and friends
You may be close to someone with HIV who's just told you that they are HIV positive. They may be well, with no symptoms of any kind or they may have been sick and got better or be sick now.

This may have been a shock for you, or you may have already known or thought of this possibility before. You may be the only person in the family who knows. If you've been asked to keep it a secret, remember that trust is very important. If you are upset, it can be hard to keep a secret. You could make an anonymous call to a HOTLINE. Sometimes it's best to be honest with the person who is confiding in you, and tell them that it will be difficult for you to keep this information to yourself.

It takes time to accept that someone close to you is HIV positive and learn to be supportive. Many people who find out that they have HIV feel isolated or scared. Sometimes they want to talk about HIV and how they are feeling, sometimes not. Each person is different. There is no one right way to help. Some ways that families and friends can support people who are newly diagnosed are:

- Offering your support.
- Being responsive to the needs of the person close to you: listening to what they have to say, trying to take your cues from them.
- Remembering that the process of accepting the diagnosis takes time for both of you.
- Giving practical support, like lending money, helping with housework, cooking, cleaning and washing up.
- Diversion: activities that have nothing to do with HIV, like eating out or watching a movie together.

Many people find when adjusting to major changes they experience a range of emotions over time. At different times people can feel angry, disbelieving, sad, resigned, distant, stressed and at some stage, accepting. This is understandable. Be patient and remember that they will probably move through a number of different emotions.

"Well, I'm 60 years old now. They told me I was infected after I got sick four years ago."
Ironsmith

Finding Out

Activity Sheet

Facilitator

How does it feel to have HIV – Role Play

Sunida: You are a young woman who is about to get married. You and your fiance decide to have an HIV test as you plan to have a family one day. The doctor rings you at home to ask you to come in and get the results of the blood test. You find you are HIV positive. You come home in a state of confusion. You walk down to the local community health centre and talk to your friend, Duangrudi, who is a nurse there. You tell your friend that you think you will die of AIDS very soon. You are desperate.

Sunida: Hi, Duangrudi, have you got a few minutes? I need to talk to you!

Duangrudi: Sure Sunida, let's go into the clinic where it's quiet.

Sunida: Duangrudi, I've just got to talk to someone – today I found out that I have AIDS! What about my fiance? We want to have children!

Duangrudi: You are a nurse at the community health centre. You see your old school friend, Sunida, coming into the centre, looking upset. Sunida tells you that she has just been told she is HIV positive. She tells you she will probably die of AIDS very soon and asks you if she can have children now? You have actually never known anybody in your circle of friends who has HIV, although you have nursed AIDS patients before. What do you say?

Sunida: Duangrudi, yesterday I spoke to the doctor, and he says I have AIDS. I am going to die!

Duangrudi: What do you mean you have AIDS. Do you feel sick?

Sunida: No, I feel fine.

Duangrudi: Being HIV positive is not the same as having AIDS. What else did the doctor say?

- Write up the role plays on the board or ask the group to break up into twos and give each person a role-play card to read.
- The two are then to role play being the positive woman and her best friend, the community nurse.
- To help participants we have included some possible opening lines to get things started.
- Participants can act out the scripts below and make up the rest.
- Then bring the group back together to talk about these discussion questions.

Discussion Questions

★ How did Sunida feel about finding out she had HIV?

★ What were the problems she faced?

★ What did she need to know?

How could Duangrudi help her?

Keeping Well

In the video, Prasert, the leader of the Association of People with HIV/AIDS in the North looks pretty healthy. As he tells us, he has not always been so well…

"Actually, I've been sick before, in fact I've been hospitalised 3 times. The last time it looked like I was at the point of no return. People who saw me thought I was surely going to die."

Like many people with the virus Prasert has been vulnerable to 'opportunistic infections'. An opportunistic infection is any disease or germ that gets an opportunity to infect people when their immune system is not working well.

There are many viruses and germs which live in healthy bodies or which we are exposed to regularly in daily life. A healthy immune system keeps these viruses and germs from making us sick, but because HIV weakens the immune system, it gives some viruses and germs an opportunity to make people sick.

The kind of opportunistic infections a person with HIV can contract vary according to the germs they have been exposed to in the past and any new germs or diseases they come into contact with.

Very common opportunistic infections that people with HIV/AIDS get include: lung diseases like pneumonia and TB, and fungal infections from thrush to cryptococcal meningitis. Some of these are mild and easily treated. Others require more intensive treatment.

Prasert was seeing a doctor regularly so that his illnesses were detected early and were able to be treated.

"I am a pretty strong person. I'm not easy to scare. But we can't fight this disease with our minds alone. We have to take care of our bodies as well."

Young HIV positive man, Northern Thailand

Keeping Well

"With the encouragement of one person and then another their health slowly improves."

Nurse Siriporn Aksornsophapun

How we can help...
People with HIV may go for years without any symptoms. During this time they won't need a lot of medical attention. However, they should be encouraged to have regular health check-ups, usually, every three to four months.

If they have regular health check-ups, their doctor will be able to measure their general health and to look for any effects HIV may be having on their health.

That's why health check ups are a good idea for people with HIV, even when they feel quite well. All healthy people get occasional minor illnesses like colds and headaches. If they see a doctor regularly, they can also be reassured about symptoms that are unrelated to HIV.

This period, when the person is well, is often the time people with HIV take steps to improve their general health. They may exercise regularly, eat healthy food, and reduce their alcohol and tobacco consumption. Family and friends can encourage people who are making these changes, and perhaps take the opportunity to improve their own health too.

As well as improving health through exercise and diet, some HIV positive people have found a number of traditional therapies useful in preventing disease, reducing stress and boosting their immune system. Traditional massage, Tai Chi, meditation and herbal medicines are all examples of these.

We discuss these therapies on page 30.

Being Sick

When people who haven't previously had any symptoms become sick, it can be a great shock. Some people have said that becoming ill can be as great an adjustment as getting a positive blood test. In addition to the worries and anxieties, being sick can raise, the person also has to cope with their physical symptoms, such as feeling ill or tired, having eating problems, diarrhoea, coughing, fevers or pain.

For a lot of people with HIV, their physical health problems are made worse by their psychological anxiety about psychosocial issues like disclosure. Some physical symptoms have become very strongly associated with AIDS. People with HIV often dread the onset of visible symptoms because they are then exposed to the fear and prejudice of people around them.

Symptoms that often arouse fear in people are skin diseases. Perhaps this is because we recall contagious illnesses like Chicken pox which also have spots. Skin diseases that are common in people with HIV/AIDS do not usually pose a problem to people with healthy immune systems and it is rare for relatives or carers to get skin infections. The virus HIV itself is not spread through contact with spots or skin rashes either. Commonly these skin infections are not serious and clear up quickly. Spots may not look pretty but they are not a health risk to HIV negative people.

Some of these conditions leave scars on the skin. Scars are not infectious. Dried skin is dead cells that do not contain HIV.

When people do have skin infections, whether they have HIV or not, they should be careful not to introduce germs or infections into broken skin.

Creating a supportive environment is a very important way to help people with HIV/AIDS.

"I may get sores, my health may deteriorate, but keeping my will power is the most important.

I have been able to pull myself together because of my morale and my friends. Because of these things I'm here speaking to you now."

HIV positive artist, Northern Thailand

Being Sick

When someone close to you gets sick...

Many people with HIV/AIDS will experience a major illness. Such an illness may be life threatening, like the ones described by Prasert and the man in the striped shirt on the video. A lot of people will recover totally from an illness of this kind, be it cryptococcal meningitis or TB. Their weight will increase and they will look and be healthy again.

Family and friends' support is very important at these times. The person with HIV needs to feel that they may recover, even from a serious illness and look forward to the future.

Often when people first get sick, life becomes more complicated for their family and carers. People's need for care will change a lot over a period of illness. Sometimes people will need to go into hospital. Other times they can recover at home and may then return to work.

Some people will be able to look after themselves, depending on how ill they are. Where possible, people should be helped to be independent for as long as possible. They may still be able to help with housework or cooking and feel part of the household.

(Ref: HIV Information Forums Collection Sydney, 1994, A Manual for facilitators compiled by the AIDS Council of New South Wales)

"Medicine can help, but keeping up morale is vital. Moral support from family and friends is crucial. All these things together keep us going."

HIV positive artist, Northern Thailand

Mental Health

Mental health means "having a life that is happy as a result of your way of thinking, your view of the world and your view of yourself"[1]. This is very important for all people, and with the social and economic stress of modern times, it's becoming harder to achieve. People with HIV/AIDS have additional stresses. Carers and families of people with HIV/AIDS may also experience stress. This is what an HIV positive man living in Bangkok has to say about stress:

"People ask me how I can live here in Bangkok, with the congestion and the traffic and the cost of living as high as it is. The truth is about 90% of people living in Bangkok suffer from stress. They are stressed by the traffic and by the chaos of travelling to and from work. If you ask me how I've been able to survive with all that stress on top of having HIV, well, I was stressed before I found out that I was infected. But I've realised that stress makes only my condition worse. I get fevers and herpes, my body deteriorates and I can't sleep, food loses all its taste. So I ask myself, what's the point of getting stressed?"

STRESS

There are lots of ways of dealing with stress. Phra Kru Sophon makes a few suggestions in the video. He says:

"If you know you have HIV you should try and take care of your health… get plenty of exercise and plenty of sleep, make peace with yourself and know you still have a chance to live a long time."

Phra Kru Sophon from Wat Doi Saket

On the right and on the next page you will find suggestions for sleeping, exercising, meditation and what to do if you feel sad.

EXERCISING

Exercise at the right level is good for your muscles, your joints, your heart and lungs, your circulation and respiratory system. It can reduce stress and help you sleep.

Health professionals generally recommend that you exercise at least 3 times a week for 15-30 minutes at a time.

Exercise should be conducted in 3 stages:

- **Warm-up**
- **Exercise and**
- **Rest and relax**

If you're new to exercise take it easy at first. Do gentle exercise to begin with like walking, yoga or swimming.

Make sure exercise is appropriate to your age and physical state.

[1] Dr Prawate Tantipipatanaskul, Suan Prung Hospital, Chiengmai

SLEEP

Sleep is a great way for the body to rest and relax. However, many people find it hardest to sleep at times when they need it most, when they are stressed or facing a lot of problems. Some people get into a pattern of not being able to sleep, perhaps not being able to get to sleep at night or oversleeping.

Some simple things that may help you sleep better include:

- Get up at the same time every day.
- Avoid sleeping during the day.
- Reduce tea and coffee intake and other caffeine drinks like 'Coke' or 'Krating Dang'.
- Do not lie awake for more than 30 minutes, get up and find a relaxing activity.
- Try relaxation exercises.

MEDITATION

Many people in the video also espouse the practice of meditation. Meditation is beneficial on many levels, physiologically, spiritually and mentally. Many temples today run lay meditation courses. Some are particularly focused on the needs of people with HIV/AIDS. If you have never seriously practiced meditation it might be best to attend a course first, whether it's a general one or one particularly for people with HIV/AIDS. Some people find that the peaceful atmosphere at temples and meditation centres is a good antidote to the stress of modern living. Many people with HIV/AIDS find that their appetite improves and that they gain weight after attending courses.

FEELING SAD

Some people do not have a problem with stress but often experience feeling sad, low or even "down". These feelings are normal and are felt by many people during different stages of the disease.

Sometimes people need a period of time to understand their problems, to come to terms with them and to think of ways of coping with them.

If possible, talk about these feelings with a good listener, someone who is supportive who can help you understand what is happening to you. You may be able to talk these through with a good friend, family member or counsellor.

KEEPING BUSY

There are mental health benefits to keeping busy or being active:

- Activity distracts people from problems and negative thoughts.
- Activity can motivate people: the more they do, the more they feel like doing.
- Activity can help people think more clearly.
- Family and friends can help you plan useful or enjoyable and affordable activities: like cooking, gardening, going to market, exercising, visiting friends and relatives.

"Try to be optimistic and create a positive environment in which to live. Don't despair and don't sit around doing nothing. Don't think about your situation too much. Do whatever it takes to keep busy."

HIV positive woman

Nutrition

One way that a lot of the people in the video have chosen to maintain their health is through healthy eating. As Dr. Maitreya Suitthajit says on the video:

"Food is medicine... Try to find food that even in small portions contains a lot of nutrition."

People's nutritional needs vary a lot, especially those of people with HIV/AIDS. Vitamin pills or tonics are no substitute for healthy eating.

Well people

In the non-symptomatic years people with HIV benefit from a nutritious or balanced diet . This means eating a variety of foods each day to supply the body with the nutrients it needs. Nutrients are the components of food and include: proteins, carbohydrates, fats, minerals, dietary fibre and water. No one food contains all the nutrients you need. Certain types of foods contain similar nutrients and can be grouped into 5 main groups called "The Five Food Groups". You should have something from each group each day, although more from some groups than others. An easier way of thinking about it is the "Healthy Diet Pyramid": You need to:

Eat MOST: fruit, vegetables, cereals like rice and flour foods like noodles
Eat MODERATELY: fish, lean meat, poultry, legumes, nuts
Eat LEAST: oil, butter, sugar, coconut cream

Eating a good range of foods makes expensive vitamin supplements unnecessary.

Some common ingredients in foods are also used as herbal medicines. Your favourite dish could be a great source of nutrition and a traditional medicine! Herbal medicines used in cooking include lemon grass, galingal, basil and ginger. '*Mieng kam*' is a dish which contains many herbs used in traditional medicine.

Traditional diets

Some traditional therapies advise particular diets and stipulate foods to avoid. If you are on one of these diets you should make sure that what you eat still provides you with all the nutrients your body needs. For instance, if you can't eat seafood, then make sure you eat fresh water fish and pork, eggs and soy beans and tofu to keep up your protein. If you are on a vegetarian diet then you need to pay particular attention to protein and calcium. Soy beans, bean curd, soy bean milk, cow's milk and yoghurt are good sources of protein. Cow's milk contains calcium and so do dark green leafy vegetables.

Sometimes people with symptomatic HIV develop specific nutritional problems. These need to be addressed on a case by case basis. Different opportunistic infections may lead to particular eating problems.

Common ones are chewing and swallowing difficulties due to throat and mouth infections, loss of appetite, diarrhoea and weight loss. See the next page for some suggestions to help with these.

"Just like me when I eat these days I also eat for the virus in my body. I eat so this virus and I can live in harmony."
HIV positive man, Bangkok

Nutrition

Facilitator

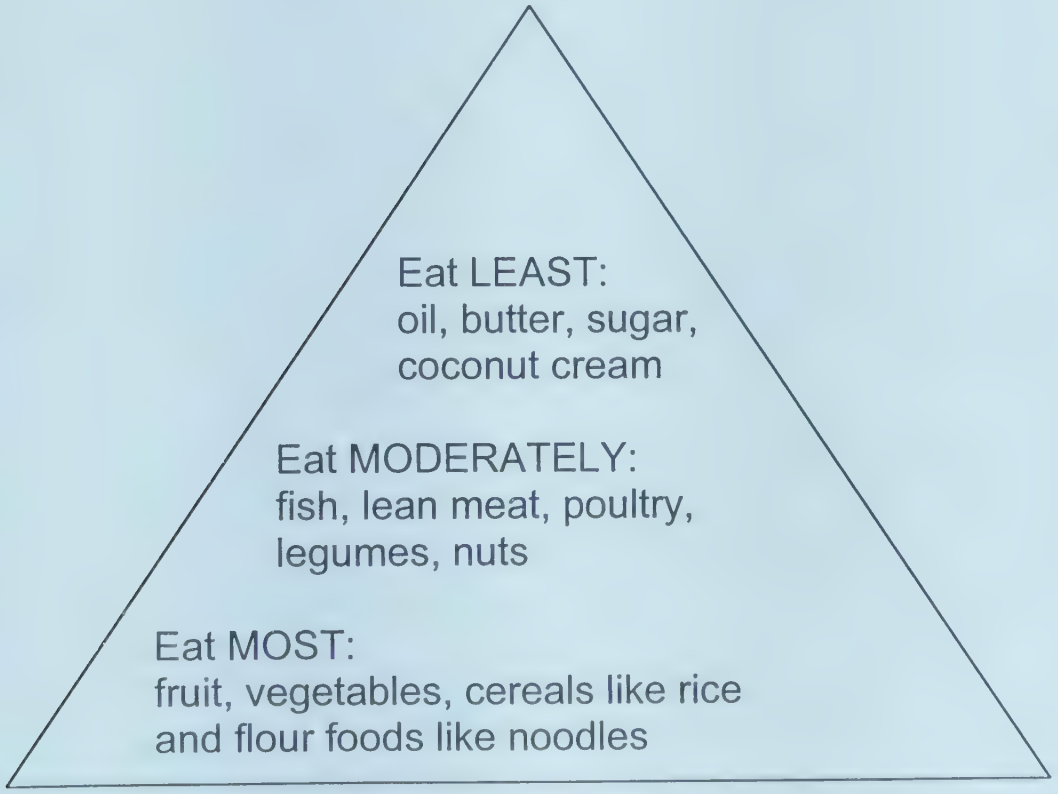
Activity Sheet

Is what you eat healthy?

Ask everyone in the group to remember what they ate over the last 24 hours and to write it down.

Then ask them to go through the foods and see if they can work out what category the food fits into.

- Did you eat something from each of the three food groups shown in the "Healthy Diet Pyramid"?
- Which of the three groups did you eat most of?



- Which of the three groups did you eat least of?

When illness affects eating…

Weight Loss

There are three food groups people with weight loss should concentrate on to build up their weight. Increase each in turn:

★ Protein
★ Energy foods (Starch and Sugar)
★ Fats and oils.

Step 1.
First try and add **more** protein to their diet: Fish, pork, chicken, beef, eggs, beans, tofu, soy bean milk and cow's milk all contain protein. Add **extra** protein to food they **already** eat, such as adding egg to everything possible (salted egg with congee, shredded omelette with noodles) and adding extra dried skim milk powder to Ovaltine or milo.

Step 2:
Then add energy foods, foods with starch and sugar like rice, noodles, bread or cakes and fruit.

Step 3.
Then lastly add fats and oils, like milk, coconut milk, coconut custards, deep fried foods.

Generally… To gain weight you should try and eat only food and drinks that are nutritious. Don't fill up on water, drink milk or fruit juice or coconut juice. Try and keep snack food and a milk drink (cow's milk, soy milk or yoghurt drinks) handy at all times.

Loss of appetite

Here are some suggestions to help you eat more.

★ If you don't feel hungry, try and eat a little, often.
★ Choose food that's high in calories to give you energy, like fried bananas, peanuts or fruit juice.
★ Avoid food or drink that's filling but low in calories, like water or Diet Coke.
★ Check and see that it's not your medicine that's making you feel sick.
★ Try and make mealtimes enjoyable: play music, eat with friends, try and make your food look pretty.

Chewing and swallowing difficulties

★ Try to eat only soft, smooth foods like eggs, steamed fish, Ho Mok, tofu, blended fruits, banana puddings and coconut custards, icecream.

★ Cut up food very finely before cooking to reduce time taken to chew.

★ With noodle soup, cut up glass noodles or other noodles in one or two inch lengths to prevent choking.

★ Thicken sauces to make them viscous and easy to swallow. You can even add a little agar-agar powder to soups to make them slippery like jelly.

★ Avoid hard crunchy food.

When illness affects eating…

What to eat when you have … Diarrhoea

Diarrhoea means that you produce runny stools more than three times a day. You may have vomiting and stomach ache as well.

Dehydration

Dehydration which is caused by diarrhoea can be very dangerous. You must replace the water and salts that your body loses in diarrhoea by drinking water with salt in it, broth, coconut juice, weak cordial or oral rehydration mixture. You can make this yourself by adding ½ a teaspoon of salt, and 2 tablespoons of sugar to 750 cc. of boiled water (a bottle the size of a fish sauce or soy sauce bottle).

Minerals

Your body loses a lot of minerals as well, in particular, potassium, which is found in bananas, tomatoes, oranges, coconut juice and fruit juice. You should try and eat some of these foods everyday.

If you have severe diarrhoea you should avoid:

- ★ Fatty foods - your body will not be able to absorb fats and oils.
- ★ Milk - lactose can cause diarrhoea.
- ★ Fibrous foods - these may make diarrhoea worse.
- ★ Alcohol and caffeine – these make diarrhoea worse.

If you have diarrhoea for more than 2-3 days you should see a doctor or a nutritionist to ask for treatment or nutrition supplements.

When your symptoms clear up you should be able to eat normally again within the week.

Herbal Medicine

Traditional herbal medicines can be a valuable resource for people with HIV/AIDS. The ingredients in traditional medicine are often cheap and some can be easily prepared. Today many people choose to combine traditional treatment with modern, they may take herbal medicines but they also see a modern doctor at the same time…

"Our hospital's basic approach to healing combines emotional encouragement with the introduction of herbal medicines as tonics. Presently we're using medicinal herbs as tonics… They increase the patient's appetite and activate the immune system. They stimulate resistance enabling the patient to fight disease. Modern medicines are used to attack and kill the virus. Here we treat patients with a combination of methods."

Dr. Thara Onchomchant MD, Phaya Meng Rai Hospital

Modern doctors and pharmacists are now researching and refining many traditional medicines. People with HIV will find that a number of books have been written about herbal medicines and HIV/AIDS. As well, magazines like "Folk Doctor" also provide up-to-date information on the latest advances in herbal medicine, with a particular focus on HIV. Newsletters of positive associations like Naam Chiwit and others also contain information on herbal medicines and HIV/AIDS. We do not have room to give detailed information on the range of herbal medicines. (See box for the traditional use of the three medicines named in the video.)

Don't forget to inform your doctor if you are taking herbal medicines! They sometimes cause side effects or may interfere with other medications. Let the doctor know how they are helping you. With herbal medicines, as with any other medicine, you need to be well informed and choose them carefully.

Here is some information that the Communicable Disease Control Office in Chiengmai has published on three of the herbal medicines mentioned in the video.

Five roots medicine

The traditional formula for "Benjalokwichien " or Five Roots is used for fevers where patient has head-ache and aching joints. It is made up of Chingchee, Kontana, Ya Nang, Tao Yai Mom and Madeuh Choompon (in rainy season, use bark or wood of plant , in dry season use roots). *Take equal quantities of all five herbs, wash and cover with water, boil over low flame until reduced by two thirds. Drink a glass of liquid remaining 4 times a day, before meals and before bed.*

Bo-ra-pet

Traditionally, Borapet can be used for loss of appetite, where the patient cannot eat at all or eats very little, and is losing weight … It can be chopped up, dried and ground to a powder, then mixed with honey to form pellets, one is taken before meals.

Fa-talai-joan

Traditionally used for chronic fever (often combined with upset stomach and headache). Infuse one or two fresh plant tips in warm water as a drink. High in potassium.

Herbal medicine must be prescribed by a Licensed Traditional Practitioner.

Ref: Holistic Self Health Care CDC 10, Chiengmai MOPH 1997

Employment

Before running this session, spend 10 minutes revising participants knowledge on HIV transmission (see page 46).

Employers' questions answered

Can positive people work like other workers?
People with HIV who are not ill are like ordinary workers in every way. Most people with HIV have no symptoms at all for many years and are strong and healthy.

After a number of years some people will have periods of illness and then recover their health. When they are recovered they are able to return to work.

Will productivity be affected by retaining HIV positive employees?
The aim of most businesses is to make a profit. Many businesses think that the easiest solution to having positive employees is to get rid of them and replace them with new employees. What many businesses do not calculate is the loss of income caused by staff turnover. Replacing workers invariably costs money. **Sacking and recruiting new workers takes time. Productivity suffers while the new employee is being employed and trained, casual staff may need to be employed for a period, extra administrative and insurance costs will be incurred.**

Can other workers catch it from them.?
Not unless their job involves having unprotected sex with other people or sharing blood or body fluids. Employers need to be informed of the Facts about occupational transmission: The virus can only be transmitted 3 ways (See page 46).

Can HIV positive people use the same bathroom?
HIV cannot be transmitted through shared use of toilet facilities.

Can HIV positive people do any job at all? What if chef bleeds into salad?
Whether or not the chef has HIV, restaurant clients and health inspectors would prefer it if you threw away that salad and made a fresh one. Normal hygiene should be observed.

"Companies that previously wouldn't have dreamed of hiring people with HIV are now giving them jobs. When people come here with HIV to work, they tell me how much better they feel, and how nice it is to make new friends who are also positive, while also feeling accepted by those who aren't infected... their spirits are lifted higher and higher."
Flower shop owner

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Employment

What about when a worker begins to experience minor health problems or the occasional illness?
If a good worker with good skills has HIV, a good manager will be able to maximise returns to the company by utilising the skills and knowledge of that person, rather than bringing out their weak point - the illness.

The case studies on the activity page demonstrate some of these issues.

What about workers who have opportunistic infections?
Workers who are ill should not be at work and should take sick leave like other workers. Some minor skin infections, such as penicillosis, may not affect ability to work.

Is it safe to visit a workmate in hospital with TB?
After a TB patient has taken TB medication for five days they are no longer infectious. Furthermore TB can only be contracted through long and close contact with someone in the infectious stage of the disease.

How flexible do employers have to be?
Ideally there should be negotiation and compromise on both sides. For instance, shorter hours will mean less money and less pay but retention of benefits.

Some employers think the easiest solution is not to employ anyone with HIV in the first place. In fact, it is not that easy to keep HIV out of your workforce. To be sure that none of your employees had HIV you would need to test them all every day. Testing would have to be compulsory, would cost time and money and affect staff morale.

Remember, you probably already work with ordinary people who happen to be HIV positive.

You already sit next to them on buses, you share public phones with them, and you eat and drink at restaurants or stalls with utensils also used by positive people everyday.

Millions of people work and sit and eat side by side with HIV positive people and have been doing so for the last fifteen-twenty years. And no one, anywhere in the world, has ever contracted the virus from doing these things.

"Positive people will say - I can still work, just give me the chance and I will work harder than others."

HIV positive man, Bangkok

Employment

Activity Sheet

Facilitator

Divide participants into small groups. Give out copies of the case histories, one to each group. Ask them to read aloud the histories and discuss the questions. Then ask them to present their conclusions to the whole group.

Case History 1: Chalerm

Chalerm, a very competent worker at a prestigious Hotel, had a number of HIV related illnesses. He had not disclosed to anyone that he was HIV positive. He began taking more and more sick leave. His friends at work noticed that he was often sick and kept asking him what was wrong. Chalerm began to feel ashamed and guilty, so he gave notice. He told the personnel manager that he was going back to the country to be with his parents and work the farm.

What do you think of Chalerm's actions?
Did he have any alternatives?
What would you do if it were you?
How could his friends at work have helped him?
Could his personnel manager have helped him ?

Case History 2: Somchart

Somchart was an older man in the civil service. He began to have symptoms that his colleagues thought were HIV related, possibly because they had all heard stories about his lifestyle and how he liked to go out partying with his friends. Somchart began spending a lot of time at the doctors. He told his colleagues he had a lung condition. He was also losing weight. His colleagues, who were convinced he had AIDS, kept asking him about his health, and suggesting that he should take time off. Each time, Somchart would say that he was fine and able to keep working. Finally, a colleague asked him to his face if he had AIDS. Somchart looked him in the eye and said "I don't have AIDS. I am able to work." He kept on working until he became seriously ill and died.

What do you think of Somchart's actions?
Did he have any alternatives?
What would you do if it were you?
Were his colleagues really trying to help him?

Both these cases are based on true stories. In the case of 'Chalerm', the hotel was reluctant to lose his skills and would have liked him to stay on in a less arduous training role.

But the hotel didn't get the chance to do this as 'Chalerm' ruled himself out.

Love, Sex & Intimacy

(See pages 46 and 47 for additional information on transmission and page 38 for a 'safe sex' activity.)

"In my opinion re-marriage is a good thing, because love is a good thing."
HIV positive young man

Having HIV does not change people's need for love and intimacy in sexual relationships. In this video we hear from two couples who talk about their relationships. One couple is made up of two HIV positive people who met and got married, each knowing the other person was HIV positive. Prasert and Lamai feel the fact that they are both positive has meant that they are better able to understand each other than most couples.

The other couple who talk about their relationship are the artist and his partner. She is HIV negative and he is HIV positive, yet they continue to have a mutually supportive relationship.

For both couples these relationships have been an important source of comfort and strength, have helped them feel more positive about life and helped them maintain their health.

Some people think that HIV positive people should not form relationships or get married after they know they are HIV positive because their lives will become harder, instead of easier, if they have to care for a partner as well as themselves. This may or may not be the case but the decision here should be left to the participants in the relationship to decide.

"If people aren't ready they shouldn't get married. But if they are going to get married, they must learn to understand each other, to see into each other's hearts and learn to share their lives together."

"I'm thinking back to when we met, four years ago. People didn't really understand us but we kept struggling until they did. All along we had to prove that people with HIV have the right to live like everybody else... The thing that makes me most proud is that we were one of the first couples with HIV to marry. We let everyone around us know that we are positive. It's a good feeling not to have to keep any secrets from anyone."
Prasert Dechaboon

Love, Sex & Intimacy

Below are two questions that many people have about HIV positive people in sexual relationships:

- **What about the possibility of sexually transmitting HIV to an uninfected person?**

If one person in a relationship does not have HIV, sex with a condom, or safe sex that does not involve penetration of the anus or vagina or mouth will protect him or her from getting HIV. (See page 37 for information on safe sex.) Many HIV positive people choose to continue or start a sexual relationship knowing that they can protect their partner from infection.

- **Is it a problem if two HIV positive people have unprotected sex?**

If both partners in a relationship have HIV, then they may want to have sex without a condom. Doctors advise that this is unwise, because partners risk exposure to more aggressive forms of HIV and to other illnesses and bacteria that can be sexually transmitted. If passed on, these could put extra strain on the immune system. Again, the final decision should rest with the partners in the relationship.

"What if my wife wasn't here! What if she'd left long ago? What would others have thought? How would I have felt? The thing is she is here. She is not infected, and yet she has stayed with me all this time. Through thick and thin she has been by my side. She comforts me and takes good care of me. But now that we have been married for 6 years we are 100% sure that she's negative. We even have a doctor's certificate. As for me I'm 100% sure I'm positive. That's something that I can accept."

HIV positive artist

Love, Sex & Intimacy

Another question that many people are troubled by is whether HIV positive people should have babies. The situation for HIV positive women who are pregnant or wish to get pregnant has changed dramatically in the last few years. New treatments, such as the use of AZT by pregnant women, are available to reduce the risk of transmission from mother to child.

When we were preparing this manual we found that most people we spoke to were confused about transmission from mother to child. People thought that **every** child born to an HIV positive mother would have HIV.

In fact, even without the new treatments only about a third of babies born to HIV positive mothers will be positive. When breast feeding is withheld, drug treatments can reduce this number by between 50 – 67%, depending on the drug therapy used. When drug is used in combination with other treatments like caesarian section, the transmission rate will be lower and could go down to 0%.

However, this question is just one of a number of issues for women with HIV who are pregnant or wish to become pregnant to think about. They may need to plan for the child's future and prepare for any difficulties that may arise. They may need to arrange alternative care, if they are unable to care for their child at any stage in the future. Talking to a counsellor, doctor, or to other positive women may help them clarify these issues.

Love, Sex & Intimacy

HOW HIV CAN BE SPREAD

We all think we know the three ways HIV Transmission can occur:

- Through Sex : unprotected sexual intercourse, (which can be *penis/vagina sex; penis/anus sex)* or oral sex.
- Sharing needles or syringes which carry the blood of an infected person into the blood stream of another.
- From mother with HIV to baby during pregnancy, birth or breast feeding.

Some people may think that when people have HIV their sexual needs automatically cease. This is not true, people with HIV continue to experience sexual needs and feelings in the same way as other people.

PROTECTION

What is really very important for everyone, these days, is to know how to protect ourselves and others, through SAFE SEX and SAFE INJECTING.

What is SAFE SEX?

Safe sex stops a body fluid that contains HIV from entering your body or from leaving your body and entering another person's body. This kind of sex can be a lot of fun! Here are some ways you can have safe sex:

Rubbing together; Kissing and hugging; Massage and touching; Mutual Masturbation;

and,

Using a condom with water based lubricant every time you have sexual intercourse. Condoms need to be used properly (See box).

- Open the packet carefully to avoid damaging the condom.
- Squeeze the air out of the top of the condom before rolling it on (bubbles of air can make it break).
- If uncircumcised pull the foreskin back before fitting the condom.
- Use water based lubricant on the outside of the condom.
- Hold the condom at the base while withdrawing penis after ejaculation.

What is SAFE INJECTING?

Safe injecting stops a body fluid that contains HIV from entering your body or from leaving your body and entering another person's body. This means ALWAYS using a new needle and syringe when you inject drugs. If you can't get a clean needle and syringe, clean a used one thoroughly:

1. Fill the syringe with clean cold water. Shake to remove all blood. Then squirt down the drain. Do this twice.

2. Completely fill the syringe with bleach. Shake for 30 seconds to clean it. Then squirt down the drain. Do this twice (use fresh high strength bleach).

3.Fill with clean, cold water again to rinse away the bleach. Do this twice. After injecting, rinse your syringe.

Love, Sex & Intimacy

Activity Sheet

Facilitator

The safe sex game
Draw up a chart like this:

Body Fluids	

Ask the group:

- **What are all the body fluids you've ever heard of?**

Write down all suggestions: sweat , spit, semen, mucous, urine, vaginal fluids etc.

In the next column write "entry points or holes".

Body Fluids	Entry points or Holes

Ask the group:

- **What are all the entry points or holes you have ever heard of?**

Write down all suggestions: anus, vagina, puncture due to needle injection, mouth, cuts, penis, eyes etc.

In the next column write "Sexual activities".

Body Fluids	Entry points or Holes	Sexual activities

Ask the group:

- **What are all the sexual activities you have ever heard of?**

Write down all suggestions: masturbation, receptive and insertive vaginal intercourse, receptive and insertive anal intercourse, licking, kissing, etc.

Now, go through the list in column one and ask:

- **What are high risk body fluids that carry HIV in sufficient quantities to transmit the virus?**

You can assess and correct their answers according to the information in the next column:

INFORMATION

HIV is present in sufficient quantities to transmit the virus in semen and blood and vaginal fluids and breast milk.

HIV is not present in sufficient quantities to transmit the virus in saliva, sweat, vomit, tears, urine, faeces, mucous.

To transmit the virus, body fluid containing sufficient quantities of the virus to infect must enter the blood stream through a hole like a needle puncture or through mucous membranes in the lining of the vagina, rectum or urethra (pee-hole in a man's penis).

Mark on the board which fluids are low risk, no risk, high risk.

Then ask:

- **What holes can HIV get in?**

Use the information to assess the answers.

Then ask the group to:

- **Assess the sexual activities listed, as: "no risk" , "some risk" and "high risk".**

Love, Sex & Intimacy

Facilitator

Activity Sheet

"Life Beyond Choosing" is the story of Lamai Dechaboon, written by herself. The facilitator should read this history carefully so that you can tell people about Lamai and Prasert if they have questions about them, in particular, or if they want to discuss issues to do with HIV positive people marrying or forming relationships.

You can also photo-copy this story and give it to people to read before starting to discuss this topic or give it to participants as a handout to take home after the session.

We have included discussion questions should you give it out to read before starting discussion. Bear in mind that it is a long story and requires a reasonably high level of literacy.

"Life Beyond Choosing" was taken from AIDSNet Newsletter Vol 1 No 1 Aug-Oct 1998 pp32-38.

Discussion Questions

- What are the positive things in Lamai's story?
- Why do you think she re-married?
- How can support groups help people who are HIV positive?
- What are the negative things Lamai experienced?
- Did her family experience discrimination?
- What was hardest for her?

Lamai's story: LIFE BEYOND CHOOSING

In 1993 my husband was so sick that he had to be admitted to hospital. The doctor had his blood tested, which revealed that he had the AIDS virus. It was hard for me to believe that my husband had AIDS. To confirm that my husband had really contracted the virus, I decided to have a blood test together with my daughter. The next day the doctor came to the bedside and told me that both myself and my daughter were infected with the AIDS virus. It really shocked me. I was so upset. Tears poured down my cheeks. I hugged my daughter tightly.

I thought so much that my head began to spin. I didn't know what to do. I felt sorry for my daughter and for myself. I had never once thought that my husband could be unfaithful. When I first learnt about what happened to my husband, I had difficulty understanding it. I couldn't imagine how he could have picked up the virus. I really believed that he had never slept around. But, what the heck, knowing about this didn't help make things better. So I tried to get over it.

Discharged from the hospital, my husband's illness got worse and worse. He became so thin that he couldn't walk. He lost the ability to hear and speak. The whole time that he was suffering I looked after him closely.

My husband was really concerned about me and my daughter. Tears poured from his eyes every time he saw our daughter come close to him. He wrote a letter to his father. Every word of the letter was a plea to take care of me and my daughter. He wanted everything he had a right to inherit to become our daughter's inheritance.

Two months later after being discharged from the hospital, he left me and our daughter, never to return again.

I decided to take my daughter back to my home village to stay with my parents. I couldn't stand staying alone in the house we had built together.

Not very long after my husband passed away, I felt that I could no longer stand to see my daughter playing alone at home. So I enrolled her in a kindergarten nearby. She began to make friends and was happy to play with those of her own age. This made me feel a bit better. Unfortunately, just a few days after she had started kindergarten class, she became sick. Later on she got sick every other week. She couldn't go to school 2 weeks in a row. She was often sick. After this had gone on for two months, the principal came to ask me to stop taking my daughter to school because other parents couldn't accept the situation. It hurt me to know that society didn't understand us. Why did they have to make things worse for people like us whose hope had been taken away and had nowhere to go? I cried from pity for my daughter for several days. My daughter cried for missing playing with her friends. I had never thought that things would turn out like this.

Hope returned to my life once again when I began to mix with friends who went to get herbal medicine in Chiang Mai. I got both friends and medicine. My suffering was reduced a little bit. At that time we joined together to establish an association called the New Life Friends Centre. Later on we got some support from NAPAC which helped boost the morale of friends who came to get herbal medicine. Working at the New Life Friends Centre, I got a small salary which was spent on the basic needs of me and my daughter. I took my daughter to the centre as well.

After I revealed myself openly to the public to let them know that I was AIDS infected, many times I had to tell the story of my life and express my ideas, even though I knew that it hurt me to talk about this. On more than one occasion I couldn't stop my sadness. I burst into tears during a meeting or seminar without feeling shame or embarrassment. I could stand to be hurt if it would help people realise their responsibilities. This awareness would help build love and understanding for people

infected with HIV/AIDS or suffering from HIV/AIDS.

My daughter was a talkative child. Many times she talked about her future while lying in the hospital. She said she wanted to be a singer so she could sing beautifully. Most of all, she wanted to be a doctor so that she didn't have to stay in the hospital since she could take care of herself. Whenever I heard my daughter talking about her future, I secretly shed tears. I knew that it was impossible but it was beyond my power to stop my daughter's imagination. I couldn't destroy the dreams of my innocent child.

It's true that we can't choose the life we have or at least no one can choose all the things to make a perfect life. In my life, even though I had to face suffering, I had the good fortune to meet some kind people and good friends.

Coins always have two sides. Even with the bad luck, there's still some good. It seems like the light in darkness. I found a man who faced the same fate as me. He was a nice guy who dedicated himself to working for society. Knowing each other, working together, we understood each other, the relationship gradually developed into love. I made a decision to remarry even though I had never thought of marrying for a second time. We were married at the beginning of 1995. I realised that he was the light to replace the darkness surrounding me and my daughter. He loved my daughter. He loved my daughter very much. He treated her as a father should treat his daughter. My daughter called him daddy. Once again I was a part of a happy family with father, a mother and a child.

My daughter was 5 years old in 1996. She was often sick. She had fevers every evening. She had to be in the hospital so often that she wondered why she had to take medicine all the time. Why didn't her friends have to go to the hospital? I couldn't answer her. Even though she was not so well she still wanted to go to school. She woke up early and got dressed. I didn't know what to do other than prepare her medicine to take to school. Teachers at school knew her condition. There were a few other pupils who were infected. During times of sickness, my daughter was very moody. One stay in the hospital lasted for 10 days.

Then finally, came an event that I never wanted to face in my life. It was November 11, 1996, when she left me. I didn't want this to happen. I had never wanted it. I was very sad. I didn't know what to do at that time. I just wanted to go with her. I worried about her so much. Where had her spirit gone?

Many people came to her funeral ceremony. The villagers came to hold my hand to give me moral support. After the funeral ceremony I didn't sleep well. I lost 5kg in weight. I missed my daughter. Later on I could get over it. I began to take care of myself. I made merit and dedicated my acquired merits to my daughter. I always do this. It is now a year and eight months but she is still always in my memory. The more time passes the more I miss her.

I still dedicate myself to work for society by providing counselling on health care, making home visits, refer patients to the hospital in case of sickness, as well as co-ordinating the assistance between the HIV infected persons with government and non-government organisations, especially children who are infected by AIDS. In the mean-time I set up the Wholistic Health Promotion Centre to let my friends with HIV learn how to take care of themselves.

From all the things I have done,
I have learnt that my life is valuable, hopeful and meaningful.
AIDS is suffering,
AIDS has given me the taste of how unreasonable people in society can be.
However, AIDS has taught me the meaning of virtue, love and understanding.

Families

Family support can be very, very important for people with HIV/AIDS. People need their families especially when they are unwell or having hard times. HIV/AIDS is no exception.

HIV/AIDS also presents big challenges to families.

When someone in the family finds out they have a serious health problem, all kinds of things can happen. Even when the person is healthy, families may worry about the future or how the person is taking the news or what other people will think when they hear the news. Later on if they get sick, there may be all kinds of extra pressures on families, like loss of income, having medical expenses and caring for the sick person. It's not easy for families when someone is sick.

Usually families need time to adjust to the news that a family member has HIV, just as the person who has the virus does. Some people's families are able to be warm and supportive from the start. But more commonly, families go through a period of adjusting. This does not usually happen overnight and can take a long time. This can be a very difficult time for families.

Over the past few years many people have had these kinds of experiences and been through difficult times. However, one thing has become very clear, family support can make an incredible difference to the quality of life a person with HIV has, sick or well. Families that have offered love and support to positive family members have been rewarded by their love and appreciation in turn and seen the health benefits.

Families may need a lot of support when they are caring for a sick person. Some hospitals and positive people's groups offer assistance for families too. This can vary from emotional support like, discussion groups or counselling, to practical support, like powdered milk for babies or home visiting.

Any family member who cares can make a difference. In some cases, nieces have looked after uncles, children have cared for parents, sisters for brothers and brothers for sisters, grandparents for grandchildren. People who are not related by blood can also be very important. Young people have been greatly assisted and encouraged by the old people in their village.

"People with HIV need to understand their families, and their families need to understand people with HIV. They can learn to live together and understand each other's feelings. The love that first bound them together, should be the same love that continues to bind them together now."

HIV positive woman

Disclosure

Although there has been a lot of education and advertising about HIV over the years, people still have misunderstandings about the nature of the virus. In some cases, they can repeat the facts from the television ads but they don't really believe them. In other cases the education campaigns have even confused people further. This means that there is still a lot of ignorance and prejudice about HIV.

Society in general has often been very judgemental about people with HIV/AIDS, not realising that people with HIV/AIDS are just ordinary people, like anybody else dealing with a serious health problem. That's one of the main reasons disclosing their HIV status is such a big issue for people who are HIV positive.

But it is also very hard to live with a serious health problem and try to keep it a secret. It can often be a huge relief to tell someone, especially someone who can be trusted. When positive people do disclose, they sometimes tell only one person in confidence. If you are that person this news may be quite upsetting and you might find it difficult to keep the information to yourself. In this case, it is better to speak directly about this with the person disclosing rather than have them find out later that you told someone else.

If someone tells you that they are positive ask them if they are going to tell anyone else and if they have a friend or support person they trust that you can speak to. You could contact an anonymous telephone counselling service if there is no one you can talk to.

Whether or not to disclose is a difficult and personal decision. HIV positive people generally do not want to risk their status becoming known to people they don't trust or know. This is because they may experience rejection or discrimination as a result. Some people may choose to become a member of an association of positive people but not tell their parents; or to tell their family but not their workmates.

Sometimes in disclosing, a positive person can get support that they would not otherwise receive: support from family, from government (like social welfare support) or from friends or peers in the same situation.

"If we keep it a secret we are anxious, but if we open up we are more at peace."

HIV positive woman

"I'm completely open about my condition in my community. I talk with the villagers. I visit friends in the village who are sick. I also help with rural development work, like finding work in the village for people who are infected, eg. we teach them to breed ducks and chicken. That way, the villagers can see that people with HIV can still benefit their communities, that they still can work and that they can help others. That makes a big difference in the way villagers think of people with HIV."

Lamai Dechaboon

Disclosure

Educating communities
In the video you will see people who have decided to tell not just one or two people but to be completely public and open about having HIV.

Many of these people had support from family and friends, which has enabled them to have the strength to go public. Others have chosen to be open about their condition in order to educate their communities. This is very helpful in reducing ignorance and prejudice for communities. Then, they can see for themselves that people with HIV/AIDS are just ordinary people. Like the man in the striped shirt says in the video: "I don't have scales or horns, I'm no different to other people".

Can communities help people disclose?
In some communities HIV positive people do not wish to disclose their status for various reasons. Sometimes it can be very frustrating for service providers to see people who need services but don't access them because they do not want to disclose their status. Sometimes it can be upsetting for families to see someone they suspect is positive, acting very depressed but refusing to talk about the problem.

Sometimes people ask, "What can we do to make that person disclose?" The answer is that you can never force someone to disclose. It is the right of the positive person to choose whether or not to disclose, to whom and how. However, individuals and communities can create a supportive environment by demonstrating clearly and unambiguously that they accept people with HIV/AIDS, do not discriminate and are not judgemental.

On a more formal level, you can invite an HIV positive educator from elsewhere to your village or community. Arrange a meal together and give your family and community a chance to demonstrate clearly that they accept positive people, can share food with them etc.

Can friends and families help a person to disclose that they are HIV positive?
In the case of families or friends who wish to help people whom they think may be HIV positive, sometimes clear statements of your unconditional support and concern for the person experiencing difficulties can be reassuring. This kind of statement may reassure them to the extent that they can tell you what is bothering them or it may reassure them that they are loved and supported even if they decide not to tell.

However, for many people, deep feelings and close relationships are not defined in words at all.

Some people might state their love and concern by cooking a favourite dish for the person they are concerned about. Some might ask a third person, a community spiritual leader or a trusted older relative to speak to the person they are concerned about.

Whatever the case, HIV positive people have the right to keep their HIV status confidential. And while society continues to discriminate against people with HIV/AIDS, disclosure will continue to be a difficult issue for HIV positive people.

Disclosure Activity Sheet

Facilitator

IS IT A GOOD IDEA TO DISCLOSE?
(10-20 minutes)

In the video, some people presented different ideas on disclosure:

"The process of becoming open about your HIV status involves a mixture of society's understanding of HIV/AIDS, the support structures available and the HIV positive person's own emotional needs in preparing to take this step. There must be a meeting point."
Prasert Dechaboon

"If you are not open, if your condition is still secret, you should ask yourself why your status must be hidden. If you cannot find a good reason, then by all means open up. There's so little to lose and so much to gain."
Nurse Siriporn Aksornsophapun

"We should have a reason for wanting to open up, you should not open up if you're not ready to. If, in your heart, you're not ready to come out, it's alright to keep it a secret until you are. That way, you can really help other people when you do tell them, but you should really know your reasons before you do."
Young HIV positive man with glasses

Discussion Questions

Ask the group to think about what these people have to say…. then answer these questions:

- Whose advice do you think positive people should take? Why?
- What are some reasons for disclosing?
- What are some reasons for not disclosing?
- Do you have ideas for good ways to disclose?
- Can you help someone else disclose? How?

Transmission

"It's not like an insect. It just doesn't jump from one person to the next."

Pimjai's mother

There are only three ways HIV can be transmitted. These days every school child can tell you the three ways HIV/AIDS is transmitted and because people see them so often, they have become bored and no longer hear or see that information when they look at or listen to it.

Still, there are only 3 fluids that transmit HIV(See box).

Perhaps because this information is so widely known, it may help to think about the virus in different ways:

There are 4 principles to HIV transmission:

1. **EXIT** - the virus must exit the body of an infected person.
2. **SURVIVE** - the virus must be in conditions in which it can survive.
3. **ENTER** - the virus must enter the blood stream of another person.
4. **SUFFICIENT** - there must be sufficient quantities of the virus present to cause infection.

ALL FOUR MUST BE PRESENT FOR HIV TO BE TRANSMITTED!

Sometimes, families or friends who care for people with HIV/AIDS at home are worried about catching HIV from the sick person.

If you are worried about accidentally exposing yourself to HIV/AIDS you need to understand HIV transmission in detail. In the next few pages we give you some ways to assess what is a risk for HIV transmission and what is not.

How HIV can be spread

- Through Sex :
  - unprotected sexual intercourse, (which can be *penis/vagina sex; penis/anus sex)*
  - *oral sex* (although this is less risky)

  In this case the fluids that transmit the virus are sexual secretions.
- Sharing needles or syringes which carry the blood of an infected person into the blood stream of another.
  In this case the fluid that transmits the virus is blood.
- From mother with HIV to baby during pregnancy, birth or breast feeding.
  In this case the fluids that transmit the virus are blood and breast milk.

Fluids that transmit HIV:

- **Sexual secretions (semen and vaginal fluid)**
- **Blood**
- **Breast Milk**

Transmission

Assessing accidental exposure

WHAT HAPPENS IF SOMEONE ACCIDENTALLY GETS BLOOD ON THEIR SKIN?
Blood from an HIV positive person, when it falls on unbroken skin is not regarded as dangerous. It cannot enter the blood stream of the uninfected person through their skin!

Accidentally getting blood on skin is a good example of how you can use the 4 principles to assess whether something is risky.

1. Did the virus **exit** the body of the person with HIV?
Yes, in the form of blood.

2. Was the virus in **conditions** where it could survive for long?
No, the virus is fragile and could not survive for long on skin. Also in this case, it would be quickly washed off.

3. Did the virus **enter** another person's body?
No, the unbroken skin did not allow the virus to get into the uninfected person's blood stream.

4. Was the virus in **sufficient** quantity to transmit?
Yes, blood contains HIV virus in sufficient quantity to transmit HIV, if it can get into a person's bloodstream.

ONLY TWO OF THE FOUR CONDITIONS ARE PRESENT THEREFORE THE INCIDENT COULD NOT TRANSMIT HIV.

However, because blood does contain HIV virus in sufficient quantities to transmit it, it is still wise to be careful around blood. Nurses wear gloves for any procedure they expect will involve blood.

In overseas countries, hospitals have very strict rules about infection control. In Australia, hospitals have a set of guidelines on how to assess an incident that could allow HIV to pass from one person to another. But, if a Nurse has an accident at work, for instance, if blood from a person with HIV splashes onto the Nurse's unbroken skin – all they have to do is **wash it off with ordinary soap and water!** The Australian nurse gets no treatment in this case. That is because the medical authorities are so sure that blood on skin poses no risk to anyone.

Common Questions

Many carers of people with HIV/AIDS worry about sores or spots or skin conditions on people with HIV/AIDS. Is the fluid in these spots a likely source of HIV transmission?

Not unless it enters your blood stream. If you get this fluid on your hands, it is not an HIV risk. However, you should not be touching sores with your bare, dirty hands. You may introduce germs or infection.

Dried sores or spots may have dried or peeling skin on them. Can the dried skin transmit HIV?

No, dried skin is dead cells that do not contain virus. The virus cannot live in dried skin.

Funding HIV/AIDS Programmes

The people with HIV/AIDS you see in this video are confident and articulate. Prasert Dechaboon, (the first person on the screen) and his wife, Lamai, like most of the other people in the video, have been involved in self-help groups for positive people. In the past five or so years they have developed new skills and gained experience through their participation in these groups. Their lives have changed dramatically as a result.

These groups are a great source of emotional support, assisting people to accept their HIV status and cope with illness and anxiety in what is often an hostile environment. Less well known is the role of these self-help groups in community education and prevention schemes. Frequently, their testimonials to their lived experience of HIV/AIDS are the most compelling component of AIDS education sessions.

The effect that these HIV positive community educators have had on their communities is enormous. Many organisations working in the field are now attempting to come up with indicators for their success in changing community attitudes to HIV/AIDS, ranging from attendance at AIDS funerals to willingness to eat with people with HIV/AIDS.

Previous research in a range of contexts has also demonstrated that people's understanding of their own need to practise HIV/AIDS prevention is improved by knowing someone with HIV.

International aid has made a significant contribution to these developments in the North of Thailand.

The involvement of people with HIV/AIDS can maximise the reach and benefit of community programs in HIV/AIDS prevention, care and support.

Support for such initiatives should be an important component of all aid programs.

Self-help Groups Role in Prevention:

- Self help groups train HIV positive people as public speakers and educators.
- HIV positive educators are an essential component of effective AIDS education.
- Provide local communities with compelling evidence of the real impact of the epidemic and the true nature of the disease.
- Self help groups liaise closely and work in concert with both government and non-government health workers.

Self-help Groups Role in Care & Support:

- **Contribute to community care programs, often working with local hospitals to visit people with AIDS in their homes.**
- **Access simple, readily accessible herbal medicines to complement available western treatments.**
- **Network with community based organisations, government services and NGOs to maximise the services available to people with HIV/AIDS.**

QUESTIONNAIRE

May we request cooperation from facilitators who have used this manual with your target groups to answer the questionnaire. Your responses will be valuable to improve the manual. Please send the completed questionnaire to UNICEF EAPRO, HIV/AIDS Unit, 19 Phra Athit Rd., Bangkok 10200.

1. You are a ..... (Please tick)

____ Volunteer
____ Community educator
____ MOPH staff
____ Peer educator
____ Youth group leader
____ Positive people group leader
____ Teacher
____ Others _____

2. You work with what group.

____ Rural communities
____ Slum dwellers
____ Students
____ Out-of-school youth
____ Others _____
____ MOPH staff
____ Community leaders
____ Employers
____ Employees

3. Which part(s) of the manual did you read? List Contents (Please Tick)

____ Accepting people with HIV/AIDS
____ Finding Out
____ Keeping Well
____ Being Sick
____ Mental Health
____ Nutrition
____ Herbal Medicine
____ Employment
____ Love, Sex & Intimacy
____ Families
____ Disclosure
____ Transmission

4. Did you use the manual when you were showing the video to a group? ____ Yes ____ No

5. What particular group did you last show the video to/use the manual with?

____ Rural communities
____ Slum dwellers
____ Students
____ Out-of-school youth
____ Others _____
____ MOPH staff
____ Community leaders
____ Employers
____ Employees

6. Which part of the manual did you and your target groups find most useful?

Useful to you _____

_____

_____

Useful to your target groups _____

_____

_____

_____

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